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## RESEARCH ARTICLE

### People with a borderline personality disorder diagnosis describe discriminatory experiences

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The psychiatric diagnosis of borderline personality disorder (BPD) attracts considerable stigma. People given this diagnosis may be characterised as manipulative, difficult, attention-seeking or untreatable. This paper describes a New Zealand study where eight people with a BPD diagnosis who self-identified as encountering discriminatory experiences from healthcare professionals were interviewed. Themes found included that discriminatory experiences contributed to participants' negative self-image and negative messages about the BPD label were communicated. A self-harm history appeared to be related to an increased number of discriminatory experiences. Connecting with the person and 'seeing more' (beyond an individual's diagnosis and/or behaviour) epitomised helpful experiences. Additionally, a relationship between stigma and the complaints process was noted. This study privileges the voice of those interviewed and may stimulate thought and discussion for services and health professionals working with this group.

**Keywords:** borderline personality disorder; discrimination; helpful practices; stigma; self-harm; complaints

#### Introduction

Borderline personality disorder (BPD) is a diagnosis of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), estimated to affect 2% of the population (American Psychiatric Association 2000, 2013). Clients diagnosed with BPD may be stereotyped as 'a therapist's nightmare' (Kellerman 1989 cited in Davison et al. 2003) and as "manipulative", "attention-seeking", or "trouble" (Gallop 1988, p. 19). A considerable body of research has established the stigma associated with this diagnosis, largely through examining the attitudes of health professionals. This paper summarises a New Zealand study which gathered the stories of clients who self-identified as having encountered discriminatory experiences from health professionals. Eight individuals with a BPD diagnosis were interviewed and transcripts analysed for themes.

#### Stigma and negative attitudes

There is a considerable body of research corroborating stigma towards the BPD diagnosis; this is largely focused on studying the attitudes of health professionals towards BPD. The research indicates that health staff tend to have strong reactions to this diagnosis, with more negative attitudes (compared to various other psychiatric diagnoses) and with less empathy (Fraser & Gallop 1993; Markham 2003; Filer 2005; Aviram et al. 2006; Deans & Meocevic 2006; Commons Treloar & Lewis 2008a; Westwood & Baker 2010; Black et al. 2011).

#### Reasons for stigma

There are several reasons why the BPD diagnosis may particularly attract stigma. Gallop (1988) discusses how stereotypes may influence what information staff pay attention to, with more recent, negative

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and vivid information becoming more accessible. In this way, 'a single incident can quickly represent the categories of "borderline" and "difficult"' (Gallop 1988, p. 20). Gallop argues that negative experiences become self-fulfilling; a nurse's dread of this diagnosis may precede an individual's admission, and can help set the stage for confrontation and negative interactions. The negative interactions may then be used to confirm negative stereotypes. Historically, there has been a lack of effective treatments for the BPD symptomology and this, alongside a low optimism for change (Filer 2005), has contributed to negativity about the diagnosis.

Others discuss how the symptoms and behaviour associated with BPD may lead to strong emotional reactions from healthcare staff (Gallop et al. 1989; Deans & Meocevic 2006; Commons Treloar & Lewis 2008a). One part of BPD diagnostic criteria is intense, unstable relationships and conflict (American Psychiatric Association 2000, 2013). It has been suggested that difficulties that staff have interacting with this group enhances stigma around the diagnosis (Aviram et al. 2006).

Staff may also believe BPD clients are more culpable in their actions and high levels of emotional distress than other mental health diagnoses; personality disorders are classified separately from mental health disorders such as depression and schizophrenia. According to Blackburn (2006), the placement of personality disorders on a separate axis in the 1980 DSM was reasoned, based on the beliefs about aetiology and clinical knowledge at the time, to allow personality disorders, which are by definition of a chronic nature, to avoid being subsumed by diagnoses like depression, which are more transient and are placed on Axis I. Paris (2003, p. xi) comments that the effect has been ironically unfortunate, creating an 'Axis II ghetto [where these diagnoses are] isolated and ignored'. One effect of this separation is that Axis II diagnoses can be perceived as not being mental illnesses and these clients as therefore being less deserving of support. Aviram, Brodsky & Stanley (2006) suggest that staff may believe these clients have more control over their symptoms than clients with other diagnoses, a belief for which Markham & Trower (2003) found some support. Additionally, self-harm behaviour,

sometimes seen as the 'behavioural specialty' of BPD (Gunderson 2008), and itself associated with negative attitudes from health staff, is frequently erroneously viewed as being largely manipulative in intent (McAllister et al. 2002; Gibb et al. 2010).

Illustrating some of these ideas is the thematic analysis completed by Commons Treloar (2009a). Staff ( $n = 140$ ) from three health services, two Australian and one in New Zealand, took part in an initial survey examining staff attitudes towards self-harm behaviour in clients with a BPD diagnosis. Staff responses to an open-ended question in the survey were then analysed for themes. Key themes established, firstly, that 'BPD patients generate an uncomfortable personal response for clinicians' (p. 31); secondly, that the health system is not resourced to meet the needs of these clients and, therefore, does so only inadequately; and, thirdly, that staff need strategies and techniques with which to work with these clients. Lastly, difficulties staff had with this client group were seen to be due to characteristics of the clients: that they were manipulative, time-consuming, self-harmed when in distress, and were constantly presenting in crisis. Striking comments from the research included: 'I have found people with BPD to be manipulative and I wonder if ... BPD is just an excuse for bad behaviour and nastiness' (p. 31); and '[O]nce labelled as BPD it is hard for the patient to be given an objective assessment' (p. 32).

A lack of specialised training may be a critical issue in staff attitudes, and several studies querying what effect various educational and training programmes have on staff attitudes have been conducted (Miller & Davenport 1996; Krawitz 2004; Commons Treloar & Lewis 2008b; Krawitz & Jackson 2008; Commons Treloar 2009b). These studies tend to support conclusions that specific training about BPD does improve staff attitudes and confidence in working with this group, although these improvements are not always maintained over time.

### *Living with BPD*

The emotional lives of clients with a BPD diagnosis are characterised by 'depression, chronic feelings of helplessness/hopelessness/worthlessness and/or

guilt, anger, anxiety, loneliness, emptiness, and boredom' (Zanarini et al. 1998, p. 201). The fifth edition of the DSM (DSM 5), describes anxiousness, emotional lability and depressivity within BPD's diagnostic characteristics (American Psychiatric Association 2013). Personality disorders (PD) are considered difficult to treat, and clients with a BPD diagnosis are noted for self-destructive behaviour and considerable use of mental health resources: ultimately, 8%–10% complete suicide (Bender et al. 2001; Paris 2003; Leichsenring et al. 2011). Research suggests this group may experience high levels of shame, suffering and self-stigma (Perseus et al. 2005; Rusch et al. 2006a; Rüsche et al. 2007).

Qualitative research examining the experiences of people with a BPD includes discussions of individuals being seen as a 'label' and encountering negative and unhelpful reactions from health professionals, and observing that past trauma is frequently overlooked as significant in their difficulties (Nehls 1999; Ramon et al. 2001; Castillo 2003; Fallon 2003; Barlow et al. 2007; Horn et al. 2007; Campbell 2008).

The research base of clients' experiences is very limited in Australasia, with one notable exception being an additional piece by Commons Treloar (2008). Three women diagnosed with BPD were interviewed about their experiences with accident and emergency (A&E) and mental health services in Australia. Amongst unhelpful treatment, the women described inconsistencies in care, lack of empathy and a lack of understanding of self-harm behaviour. The author concludes that: 'Negative responses, whether communicated unconsciously or consciously to the patient, have significant impact on the engagement of the patient in treatment' (Commons Treloar 2008, p. 29).

### ***Construction and validity***

It is useful to note that BPD is a diagnosis of contention: throughout its history, its validity, construction and classification have been challenged, both within and without the psychological fraternity. Current understanding that the symptoms of BPD can remit, sometimes even within a year (Zanarini et al. 2003; Gunderson et al. 2011) have

caused some to question the very notion that it is a personality disorder at all, while others have argued that BPD is better understood as a bipolar spectrum condition (Akiskal 2004).

It has been argued that BPD is a form of complex post traumatic stress disorder (PTSD) and that, in some cases, PTSD is misdiagnosed as BPD (Schwecke 2009). PTSD is acknowledged as having an overlap with this disorder (Dahl 1995), with one study finding 30% of those diagnosed with BPD also met criteria for PTSD (Pagura et al. 2010). Shaw & Proctor (2005) argue that trauma is obscured as a causal factor in the diagnosis of BPD; clients who have survived abuse are seen as having difficulties because they 'have BPD' rather than having difficulties related to their past experiences. They contend that this response of 'denial and distortion' (Shaw & Proctor 2005, p. 486) echoes society's historical response to child abuse. Additionally, with females making up 70% or more of those diagnosed, feminist critiques have highlighted the gender disparity and have questioned the ways the diagnosis may pathologise expressions of distress or trauma in women (Simmons 1992; Becker 1997; Wirth-Cauchon 1997; Nehls 1998; Kerr 2004; Paris 2005a,b).

### ***Mental health discrimination in New Zealand***

The client group diagnosed with BPD may be particularly vulnerable to experiences of mental health stigma and discrimination due to the onset of the condition in early adulthood, and its sometimes chronic course (Rusch et al. 2006b). Those diagnosed may have had multiple psychiatric hospitalisations. While other mental health conditions may be at times 'invisible', physical scars from self-harm behaviour may be noticed by others and may themselves lead to stigmatisation/discrimination.

It is widely recognised that stigma/discrimination related to mental disorder can have adverse effects on self-esteem and help-seeking behaviour, which can in turn have long-ranging effects on an individual's quality of life and health outcomes (Hinshaw & Cicchetti 2000; Corrigan 2004; Kane 2006). Hinshaw & Cicchetti (2000, p. 559) conclude that existing empirical research has not 'even

begun to document the actual levels of harm related to the stigmatisation of mental disorder'.

The public health anti-discrimination campaign, Like Minds Like Mine (LMLM), has highlighted the issue of mental health discrimination in New Zealand. Alongside the Mental Health Commission, LMLM has been involved in supporting research projects exploring the perspectives of those experiencing mental illness and their families (Peterson et al. 2004; Barnett & Lapsley 2006; Barnett & Barnes 2010). The discrimination identified in these research projects includes discrimination from health professionals (Peterson et al. 2004) aligning with wider research and commentary that health professionals may act as potential stigmatisers towards those with mental illness (De Ponte et al. 2000; Beales 2001; Corker 2001; Ross & Goldner 2009).

### ***Researching discriminatory behaviour***

While stigma is concerned with problems of attitude, discrimination queries the behavioural results of these attitudes (Sayce 2000). Thornicroft et al. (2002) found researching discrimination and abuse to be a high priority for mental health service users. Service users have commented on negative perceptions about personality disorders; with individuals being seen as their personality disorder 'label' and encountering negative and unhelpful reactions from health professionals.

While existing research has investigated the perspective of those diagnosed with BPD, and identified stigma as a significant issue, the study described here goes further by querying participants' 'discriminatory experiences'. It has been argued that using the term 'stigma' interchangeably with the term 'discrimination' can imply that responsibility for negative behaviour belongs to those stigmatised (Link et al. 2004), and Peterson et al. (2008) add that the term 'discrimination' has additional moral connotations which can assist in activist work. Additionally, by investigating 'discriminatory experiences', this study implicitly affirms service users' ability to evaluate their experiences without attempting to establish in any concrete sense whether discrimination, a term with a legal definition, had taken place. Health professionals were identified as the group

where discriminatory experiences might take place, as it is largely in the health context where the diagnosis and label of BPD may be used; those who do not have connection with health or social service settings may not ever encounter this term.

### ***Methodology***

The study was undertaken as part of a Masters of Social Practice and utilised semi-structured interviews. The Unitec Research Ethics Committee (UREC) gave study approval with the proviso that the following statement was included with results: 'Because the study has such a small sample, generalisations cannot be made from these results about the experiences of people with a diagnosis of BPD (whether or not they identify as having experienced discriminatory behaviour)' (UREC, pers. comm. 2010).

### ***Recruitment and consent***

Articles promoting this study featured in three mental health awareness e-newsletters asking people with a BPD diagnosis who identified as having encountered discriminatory experiences with health professionals to make contact if they were interested in being interviewed. The study directly recruited for those who considered they had encountered discriminatory experiences, as it was interested in building on the research base around BPD discrimination and stigma, not in examining or evaluating this client group's experiences with health professionals in general.

Participants needed to be over 18 and to self-identify as 'not in active crisis'. This latter criterion aimed to facilitate the participant's informed consent and minimise potential distress for the participants in revisiting their discriminatory experiences. Interested and eligible people were mailed or emailed comprehensive information sheets. A flow-chart, (made redundant due to the small recruitment response) was developed to gain ethnicity and gender variation in participants. Participants were not asked to undergo an empirically validated method of diagnosing BPD, only to confirm that they had received the diagnosis at some point. The recruitment

text noted that a person need not necessarily agree with their diagnosis of BPD to participate, because the study aimed to investigate participants' views of discriminatory experiences and was not concerned with the legitimacy of the diagnosis. Any interviews were booked at least a fortnight after the participant received the study information and their formal consent was gained just prior to the interview.

### ***Support for interviewees***

Support for participants was an important consideration: interviewees were invited to bring a support person and given preparatory forms which encouraged them to consider their support systems and coping strategies. In addition they were given contact details for various support services, as well as a phone number for a crisis counsellor who was directly informed about the study. Participants were asked to nominate a pseudonym; pseudonyms chosen by the interviewees are used throughout this text. Following the full transcription of the interviews, participants were mailed a copy of the interview text to confirm its accuracy. Participants were also informed that they could request partial deletions from the transcribed interview text. All participants confirmed the accuracy of their transcripts, with several correcting small details in the transcriptions. No participant requested any deletion of text. The semi-structured interview schedule was enclosed with the ethics application; Fig. 1 provides an extract of this. A sole interviewer/researcher was used. The text of the interviews was fully transcribed and analysed using a process influenced by interpretative phenomenological analysis (IPA) illustrated in Fig. 2.

### ***Interpretative phenomenological analysis***

Interpretative phenomenological analysis is a qualitative methodology underpinned by phenomenology and hermeneutics which focuses on the meaning that participants make of their experiences (Smith & Osborn 2008; Smith et al. 2009). The approach acknowledges that interpretations of each participant's experiences are inevitably shaped by

the researcher's own experiences (Smith et al. 2009). In other words, a researcher's contribution to the analysis process is acknowledged with the recognition that access to the participant's world 'depends on, and is complicated by, the researcher's own conceptions' (Smith & Osborn 2008, p. 53). This researcher's perspective was shaped by varied experiences as a counsellor, peer support worker, heterosexual woman, New Zealand Pākehā and historical experiences as a mental health service user.

The analysis of themes was widened through peer debriefing consultations on individual interview transcripts, where four individuals (psychiatric assistant, health promoter, manager and researcher) who had worked in the area of mental health were emailed an interview transcript and asked to record their thoughts on the themes they noted. The researcher then met with these individuals to discuss their ideas. Member checks were also used with two participants, with a preliminary analysis of themes noted within their interview mailed to them for comment. In addition, the researcher used journaling and supervisors for consultation and debrief after interviews and during the analysis process.

### ***Findings***

Findings of the study can be divided into two thematic areas: firstly, the impact of the participants' experiences, both helpful and discriminatory. Discriminatory experiences contributed to participants' negative self-image. Negative messages about the BPD label were communicated and a self-harm history appeared to be related to an increased number of discriminatory experiences. Connecting with the person and 'seeing more' (beyond an individual's diagnosis and/or behaviour) epitomised helpful experiences. A second theme included a relationship between stigma and the complaints process.

### ***Participants***

Seven women and one man, drawn from five district health board localities within New Zealand and aged between 25 and 65, took part. All participants identified with Pākehā/New Zealand European ethnicity, while two participants also identified with



**What discriminatory experiences related to your borderline personality diagnosis have you had from health professionals? (If you have many experiences you may like to think about the most significant or typical ones)**

*When was this experience?*

*In what setting?*

*Can you tell me a little more about the situation?*

*What happened next?*

*What did this situation/experience mean for you?*

*Was this situation typical of the treatment/person or not?*

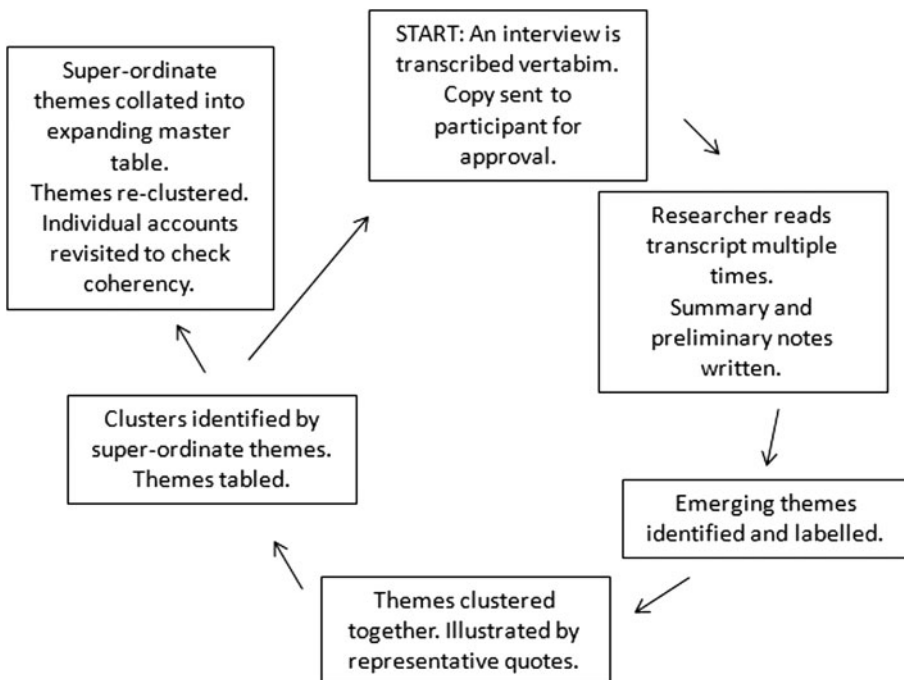
*Were you able to speak about your experiences to anyone?*

**Figure 1** Interview schedule extract.

several Māori iwi, and one concurrently identified as Samoan. Participants were not asked whether they were currently accessing mental health services, although five disclosed receiving this support.

The discriminatory experiences showed wide variation, yet took place principally in public health

services and within the last 12 years. Discriminatory experiences involved a range of professionals including psychiatrists, psychologists and general practitioners (GPs), with A&E staff and crisis teams mentioned several times. Most interviewees described multiple discriminatory experiences across multiple



**Figure 2** Analysis process. Adapted from a process described by Smith & Osborn (2008).

settings: in two interviews, the discriminatory experiences were largely related to a single professional.

### ***Self-harm and discriminatory experiences***

Participants with significant histories of self-harm behaviour related more incidences of discriminatory experiences. For example, one participant, Mel, detailed a doctor suturing a laceration without anaesthetic, giving the justification that she was dissociated and had not felt pain at the time she inflicted it. Similarly, another interviewee, Cate, described how a doctor asked whether she wanted anaesthetic while he sutured, commenting, 'Well, you obviously did this to yourself, so you like pain'. Anna, upon surviving a paracetamol overdose, had her GP suggest that she prescribe her another '500 panadol'.

### ***Negative messages about BPD***

Participants perceived negativity from health professionals connected directly to the BPD diagnosis. Perceived negative messages in their accounts included that people with BPD were: liars, attention-seeking, unreasonable/difficult, manipulative, and taking resources from other patients. Anna learned that BPD clients were to be put 'in the too hard basket ... that we just do things to gain attention'. Likewise Cate, who had entered the mental health system in her teens, described receiving the message that clients with BPD were a waste of time or hopeless, particularly as they did not/could not get better. She described learning that 'the best we [BPD clients] can expect is to do the least amount of damage to ourselves as possible and this is going to be our lives'.

### ***Negative impact on self-image***

Discriminatory experiences negatively impacted how participants saw themselves; several referred to feeling that they were not as human as others. Participant SK observed: '[As a result my] self-worth had gone, self-confidence had gone, thinking that I was different because I was missing something ... but not knowing how to get past that point'.

Anna made the comment: 'It just felt like I was being abused all over again'. Delia had concluded from her experiences: 'I'm a write-off as a human being, not just as a mother but I just shouldn't be here. Not that I wanted to kill myself, but I was just a waste of space and a waste of time'.

### ***Stigma and complaints***

A connection between stigma and complaints appeared as a theme of interest; when asked directly about whether they had made any complaints about the treatment they had received, half the participants had done so on at least one occasion. Complaints were difficult to make, and none of the interviewees who had made complaints reported a satisfactory outcome. Anna discovered that she could make a complaint about therapy practice she considered inappropriate and in the resulting meeting she brought along an advocate. The psychologist whom she had raised the complaint about had brought her own support person advocate; this person also held the role of being Anna's occupational therapist. Anna describes the resulting mediation meeting:

I actually hadn't been told until that day that I had the diagnosis of borderline. And she sat there, the psychologist, and she just talked to the advocate, she didn't talk to me. And she goes 'oh this is typical behaviour for someone with borderline personality disorder'. And I'm going what? And when I left I went straight to the library to find out what on earth she was meaning.

Anna also described the way this complaint led to her having a 'bad name' within mental health services as someone who 'made complaints'; something she found difficult to grapple with given it was the first time she had ever made a complaint and that at the time she was new to the mental health system. Unsurprisingly after this experience, regardless of how she was treated, Anna did not make any further complaints. Emma, who had mentioned to a group facilitator that she was having difficulties with her therapist, was encouraged to take it up with the therapist. Emma did not feel able to do this saying: 'I felt like laughing and saying,



well I can't talk to him about ANYTHING so why would I then say to him "I don't like you and I don't like the way you treat me sort of thing".

Mel explained why she did not make complaints:

Oh, I'm just a consumer, what would they think, would they REALLY take any notice? ... It was just a waste of time, because I was a waste of time ... if I don't matter, why would what I say matter?

SK commented on how he had experienced his complaints as being discounted due to his status as a mental health client; perhaps particularly as he was a mental health client who had experienced symptoms of psychosis. When SK raised his concerns about a comment that a doctor had made, he was told: 'You're unwell—he probably didn't say it'.

### ***Helpful behaviour: connecting; seeing more***

Participants were asked about what they had experienced as helpful from health professionals. 'Connecting' (through caring and building relationships) and 'seeing more' (beyond the diagnosis; the context of the person's behaviour; seeing the person as human) linked the helpful experiences shared. In Emma's words: 'Seeing someone as human' included the concept of seeing individuals as worthy of respect and 'normal ... Normal—just like the rest of us ... People with BPD ... have families that they love and care about. It was like [the BPD] was a part of who I was. It wasn't everything that I was'.

Mel expressed: 'We're a human-being [sic] with thoughts and feelings and shit that's gone on in our lives. Let's not look at all that ugly shit for a minute, look at the person in front of you that's [sic] hurting'.

Part of the notion of seeing the person as human meant also seeing that they had strengths and lives outside of the therapy room, as this exchange reveals:

SK: With them focussing on strengths, it helped me to start focussing on strengths.

Researcher: What did that mean?

SK: It started giving me hope and—it started [me] actually focussing on what strengths that I had. It

gave me more strength to be able to push forward and utilise my strengths.

The theme of 'connecting' referred to a professional building a relationship with the individual, particularly through taking time, showing interest, and communicating caring and respect. As Anna observed: 'She listened and validated what I was experiencing and stuff. And it helped her to like gain an understanding of maybe why I was behaving the way I was'.

### ***Individuals have an impact***

When questioned about helpful experiences, every participant recounted anecdotes of individual practitioners who they clearly remembered. In Emma's case: 'Definitely my very first counsellor is the guy that saved my life,' while Mel described what her GP's respectful and enquiring manner meant to her: '[A] professional was looking at other things to try and help ... Just that he cared really. That he did actually give a shit'.

Participants noted these professionals offering them hope. Cate described a significant relationship with a nurse: 'I just got that flicker of ... maybe ... If this person is willing to invest in me then maybe I'm worthwhile'. At the time of this relationship Cate was recovering from a near-fatal suicide attempt. When interviewed, Cate was a health services manager and maintaining a level of wellness previously inconceivable to her. Bea, reflecting on her progress, offered thanks for the professionals who had supported her, commenting: 'They believed in my ability to heal when I didn't'. She also added, '... all I can say is thank God they [the health professionals] were there, cause [sic] otherwise I wouldn't be doing this [taking part in this interview]'.

### ***Contrasting ideas***

Ideas gathered from the research about discriminatory versus helpful behaviour are contrasted in Fig. 3.

## **Discussion**

The findings of this exploratory study support themes well established in existing knowledge.

For example, stigmatising ideas the participants perceived from health professionals about the BPD label align with the ideas mentioned in research about what service users have experienced and about health professionals' attitudes, which suggest that strong negative ideas may be attached to the label of BPD. A phrase used by two participants about BPD clients being in the 'too hard basket' or 'too hard pile' is a direct echo of a quote reported from the Australian research by Commons Treloar (2008, p. 28) where the service user comments: 'I was being passed from pillar to post. I was in the too hard basket'.

An association between increased discriminatory experiences and self-harm histories is not surprising given what is known about how this behaviour is perceived. Proctor (2007) has argued that DSM criterion of self-destructive behaviour is given disproportionate weight when making a BPD diagnosis; a situation that could then lead to self-harm stigma and BPD stigma being in many ways commensurate; those seen with repetitive self-harm wounds may be viewed through the lens of the 'borderline' label regardless of its applicability to the person's situation.

A negative impact on self-esteem was noted from the discriminatory behaviour; this is an unsurprising result as negative ideas about the self may be especially available to those diagnosed with BPD (Joyce et al. 2003). Due to the availability of these negative ideas, clients with a BPD diagnosis might be viewed as particularly vulnerable to perceived discrimination due to the likelihood that any stigma from professionals may be interpreted as legitimate (Corrigan & Watson 2002). Negative impacts of discriminatory treatment could therefore be seen as cumulative for clients who are already struggling. Health professionals may wish to be aware of this area when seeking to engage with and assist this client group. Stigma and discrimination may be an understandable consequence of staff lacking resources, training and/or being confronted by ongoing behaviour they may find personally and professionally difficult to understand or to have compassion for (Aviram et al. 2006). However, understandable does not mean appropriate or effective.

The experiences described by some participants regarding making complaints provide food for thought; the idea that making complaints is typical behaviour for someone with a BPD diagnosis seems to be a powerfully silencing one, positioning the client as someone whose complaints are trivial and/or pathological. The idea of BPD diagnosed clients as prone to making complaints probably also has ties to this client group being seen as difficult and angry, and being responsible for 'splitting' staff (Gallop 1985). This theme raises some important and challenging questions about how complaints are managed: How does stigma about the perceptions of those with mental health conditions impact upon how complaints are dealt with? And how might the resulting self-stigma act to prevent these complaints being made at all?

In Emma's situation, (described above) she was encouraged to take her concern/complaint directly to the staff member involved. This practice is one that is recommended in the treatment protocol of the BPD specific treatment, dialectical behaviour therapy (DBT), the therapy Emma was undergoing, to prevent team members becoming divided over a client's care, or for the concern or difficulty to derail therapy goals or progress (Linehan 1993). While this practice likely has many useful effects, it is underpinned by an idea that the staff member will be open and receptive to this conversation; and that both parties have an equal chance of their viewpoints being heard. It ignores the power differential in the therapist/client relationship and positions the therapist as one who will do no (further) harm.

Formal or informal complaints are one of the only ways a service user can indicate practice which may be inappropriate or harmful, and as such, provide important feedback to health services. However, BPD stigma may impact on how complaints are viewed by services/health professionals and also may influence whether or not a service user makes a complaint in the first place. Potter (2006) likens BPD clients saying they would make a complaint if not treated 'in the way they thought was right' to strike action in the labour movement which has resulted in improved conditions for workers: for clients with a BPD diagnosis, Potter notes that complaining behaviour is labelled as manipulative

<p><b>See the diagnosis</b>  <i>Prior to having this label I had quite reasonable respect and support from the psychiatric profession, but not after having had that label - Israel</i></p> <p><b>Assume you know what's going on</b>  <i>[Staff] didn't even know any of my history at all when they were making all... these assumptions. - Anna</i></p> <p><b>Treat me with contempt</b>  <i>He showed contempt for me in his tone of voice -Israel</i></p> <p><b>Get overwhelmed and caught up in the drama</b>  <i>Somehow I pressed her [crisis nurse's] buttons and she was annoyed with me... She screamed at me and hung up.... -Bea</i></p> <p><b>Focus on negative behaviours</b>  <i>[Helpful nurse] saw that underneath this behaviour these people were smart, intelligent, warm, mostly honest, affectionate caring people and ...all these [other professionals] were focussing on this [negative] behaviour -Cate</i></p> <p><b>Dismiss my pain and point of view</b>  <i>[When I had been placed in police cells,] [the psychiatrist] said to my dad, "don't worry he was just overreacting to his emotions. It's nothing to worry about -SK</i></p> <p><b>Don't believe things can change for me</b>  <i>[Professionals] were seeing what they wanted to see I think, which was very much fitting with that diagnosis of you're not helpable -Cate</i></p>	<p><b>See me as an individual</b>  <i>I think the ones that were good it was that they saw me as more than just my diagnosis. They saw me as a real person. -Emma</i></p> <p><b>Enquire about what's going on</b>  <i>"It was just being human! You know, asking more about what was going on for me" -Mel</i></p> <p><b>Treat me with compassion</b>  <i>You have to be human with them [clients]. Even if it's just you put your hand on their hand and you just go, "Okay I'll listen." -Delia</i></p> <p><b>Stay calm and centred</b>  <i>I think not to buy into the drama is probably the most important thing. -Delia</i></p> <p><b>See my strengths and my life in context</b>  <i>"With them focussing on strengths, it helped me to start focussing on strengths -SK</i></p> <p><b>Take me seriously/Validate me</b>  <i>[When they could] reflect this [distress] is a normal response ... "Shit I'd be grief-stricken too if that happened to me- I'd be angry!" -Delia          [The counsellor] actually said, it sounds like you've had a lifetime of feeling depression and a lifetime full of struggles -Anna</i></p> <p><b>Be hopeful about my future</b>  <i>There's always hope and there is always a way of reaching someone -Delia</i></p>
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**Figure 3** Unhelpful versus helpful behaviour.

in the clinical literature. Fig. 4 provides a conceptualisation of how the process of a service user not being taken seriously, or perceiving that their complaint is not being taken seriously, can result

in a silencing of further complaints, so that health-care practices are not being critiqued and improved. In this way potentially unsafe and discriminatory practice may not be noted. Services may like to

consider whether their processes support and acknowledge the viewpoint of service users who register a complaint, regardless of whether the complaint is eventually deemed valid.

The aspirational New Zealand Blueprint for mental health services (Mental Health Commission 1998, p. 17) declares that ‘when service-users are unhappy with a service, they must have a fair and easy process for making complaints’. Perhaps a fair and easy process should include a concern that both parties leave the process with the impression that their view points are heard, particularly the service user. If a service user leaves the process feeling respected and that their position has been heard, it is likely that the processes leading to silencing of complaints mapped out in Fig. 4 would be interrupted. The themes in helpful behaviour echo extensive research about what is effective in interactions with clients and service users, offering a reminder of the paramountcy of respect within the clinical relationship. Linehan (1993) goes so far as to say that simply liking this group of patients is strongly correlated to helping them, a conclusion which appears in line with the themes noted within helpful experiences in this study.

The finding that participants long remembered individual professionals who cared appears significant. Health professionals may also encounter BPD clients more frequently when things are especially difficult, particularly if they work in A&E or inpatient units. Additionally, BPD clients may find a focus on their own improvements as invalidating of their ongoing distress (Linehan 1993). Collectively, these factors mean professionals may not witness, or have communicated to them, the positive impact of their contribution, and ‘burnout’ may be a factor for professionals working with those diagnosed with this disorder (Perseus et al. 2007). Potentially, the finding that participants remembered individuals who cared is encouraging to professionals working in a challenging field. It should be noted that communicating hope in the ability of BPD clients to change works directly to contrast the stigma that BPD is a hopeless diagnosis, and is supported by research that change is possible and realistic (Gunderson et al. 2011).

## Limitations

The findings of this research reflect the views of eight service users interviewed and cannot be concluded as representative of this client group, particularly as the study selected for those who identified themselves as having faced ‘discriminatory experiences’, itself a nebulous phrase.

The gender imbalance of participants was a limitation. One significant limitation is that interviewees were not asked to limit their experiences within a recent timeframe. It is anticipated that changes in mental health treatment over recent decades have had a positive impact on BPD stigma, and indeed one participant, Cate, commented on positive changes she had seen since the implementation of DBT.

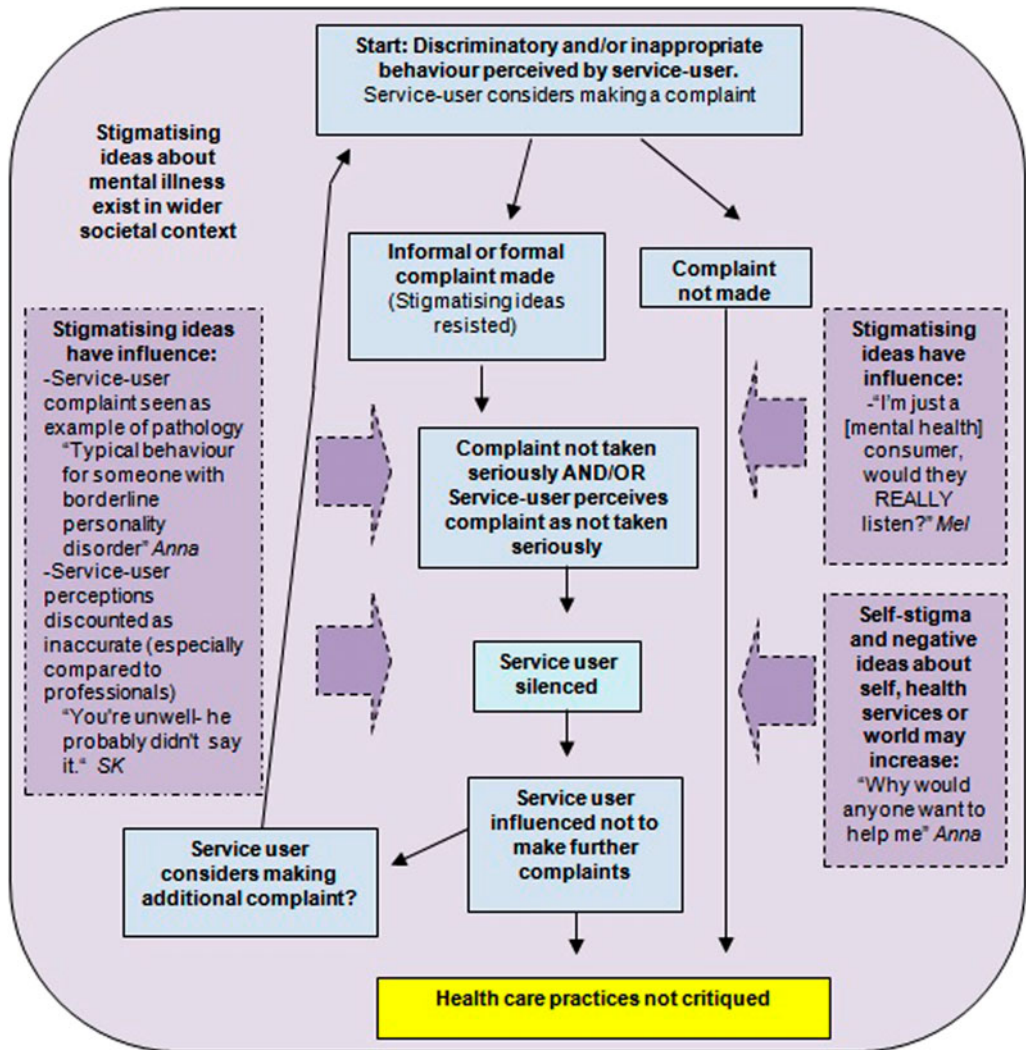
I think the thing about DBT was that even the most cynical people [health staff] could see, after they did a few pilots and did a few groups that there were these people [BPD service users] who were seemingly moving on ... It kinda gave them a reason ... to want to work, to want to try with people again.

It is unfortunate that there are no studies comparing service users’ experiences before and after the advent of specialised treatment approaches such as DBT (Linehan 1993) or mentalisation based therapy (Bateman & Fonagy 2004). The availability of these treatments may especially have supported changes in attitudes that indicate BPD has a hopeless and untreatable prognosis.

It could, however, be argued that it is of interest that participants nominated themselves to take part in a study to share incidences with health professionals that, in some cases, took place over a decade ago; perhaps this is testament to the lasting impact of negative treatment experiences. Simultaneously, it should be noted that incidences shared included those that had taken place in the last few years, one including a DBT therapist. Cate, who made the above comment about the changes seen, and was currently employed in the health system, concluded her interview with ‘... [stigma/discrimination] is better ... it’s still got a long way to go though’.

This study may be criticised as negative in focus, despite the sub-question around helpful experiences aiming to provide some balance. Findings in this





**Figure 4** How stigma may operate in the complaint process. This diagram only illustrates processes where complaints are not taken seriously or are felt by the service user to have not been taken seriously.

study may be critiqued due to concerns that participants may not be able to interpret or recount situations accurately, especially where long periods of time have elapsed; however, these critiques form part of the overall critiques of qualitative methods (Smith 2003). The longevity of people's negative experiences with professionals is further testament to the need for constructive, hopeful approaches.

While the researcher was motivated to undertake the study because of her experiences within

the health system as a practitioner and client, interestingly, one impact of her positioning was concern about how the study and results might be negatively viewed, given her open disclosure of having experienced mental health issues, and the analysis was undertaken with this concern as a constant presence. A second interviewer/researcher may have increased the perceived robustness of the analysis. The inclusion of a second researcher, perhaps without experience of mental health issues,

may also have mitigated potential concern around the ability of the researcher to conduct considered research: at the same time it is useful to place a critical lens on whether concern in this area can itself be indicative of stereotypes of the potential lack of objectivity or validity of the skills and viewpoints of those who are, or have been, mental health service users. The area of stigma and any impact on research process and identified 'service user' researchers may be worthy of investigation for those interested in supporting research led by consumers, or with previous first-hand experience of mental health issues.

### Further research

Further study might compare themes found in this study with those found in larger groups with this diagnosis, or other diagnoses. Research querying the validity of, and extending, the ideas contained in Fig. 3 on helpful versus unhelpful behaviour and Fig. 4 on complaints and stigma, will be of interest to both service users and providers. It is thought that both of these areas have potential applications in training and improving services. In addition, research which identifies what variations exist in the stigma and discrimination experienced by service users based on diagnosis, might contribute to the research base and potentially provide information for stigma prevention programmes.

### Conclusion

The contribution of this exploratory research is that it puts a spotlight on the issue of discrimination and stigma towards the BPD diagnosis in New Zealand. Although its perspective is limited to the eight individuals interviewed, the emerging themes provide areas of consideration for professionals wishing to develop or examine their practice with those diagnosed. The distinctive finding that positive interactions from individual practitioners are long remembered by clients, and continue to have a helpful and hopeful effect, might offer encouragement to professionals who offer time, positive regard and compassion to this client group.

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